

Prostate cancer and supportive care: a systematic review and qualitative synthesis of men's experiences and unmet needs

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Prostate cancer is the second most common cancer in men worldwide, accounting for an estimated 1.1 million new cases diagnosed in 2012 (www.globocan.iarc.fr). Currently, there is a lack of specific guidance on supportive care for men with prostate cancer. This article describes a qualitative systematic review and synthesis examining men's experience of and need for supportive care. Seven databases were searched; 20 journal articles were identified and critically appraised. A thematic synthesis was conducted in which descriptive themes were drawn out of the data. These were peer support, support from partner, online support, cancer specialist nurse support, self-care, communication with health professionals, unmet needs (emotional support, information needs, support for treatment-induced side effects of incontinence and erectile dysfunction) and men's suggestions for improved delivery of supportive care. This was followed by the development of overarching analytic themes which were: uncertainty, reframing, and the timing of receiving treatment, information and support. Our results show that the most valued form of support men experienced following diagnosis was one-to-one peer support and support from partners. This review highlights the need for improved access to cancer specialist nurses throughout the care pathway, individually tailored supportive care and psychosexual support for treatment side effects.

Keywords: prostate cancer, supportive care, systematic review, peer support, specialist nurse, qualitative synthesis.

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INTRODUCTION

Prostate cancer is the second most common cancer in men worldwide, accounting for an estimated 1.1 million new cases diagnosed in 2012 (Globocan, 2012). This figure has been rising due to increased use of Prostate Specific Antigen (PSA) testing (Ferlay *et al.* 2008). Men with prostate cancer are likely to have a long illness pathway, and as well as the individual burden to patients, this also represents a burden on healthcare resources. One way of managing this is to provide good supportive care for men which 'helps the patient and their family to cope with cancer and treatment of it . . . helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease' (NICE 2008). Supportive care will ideally involve strong elements of self-care, in order to encourage independence in managing symptoms and side effects (Cockle-Hearne & Faithfull 2010). However, the available guidance on supportive care and self-management tends to be generic to all cancer patients (NCSI 2013).

A recent survey in seven European countries and involving over 1000 men found that 81% of the respondents had some unmet supportive care needs (Cockle-Hearne *et al.* 2013). These findings echoes earlier surveys in Australia and the UK showing that the areas of greatest need were for psychological distress, sexuality-related issues and managing of enduring lower urinary tract symptoms (Steginga *et al.* 2001; Ream *et al.* 2008). Other studies highlight the need for the provision of information to patients and carers throughout the disease pathway (Gulavita *et al.* 2000; Sinfield *et al.* 2009). The psychological distress that many men with prostate cancer experience is not always assessed or managed well. A study from Germany looked at adjustment to disease and suggested that up to 20% of patients might benefit from mental health support following prostatectomy (Kohler *et al.* 2014). Research also reveals that post-treatment care from nurses had a significant positive impact on health outcomes (Cockle-Hearne *et al.* 2013).

Surveys of unmet need make a case for improving supportive care but an important step is to clarify men's experiences of support using qualitative research methods. Many qualitative studies have been carried out looking at men's experiences of prostate cancer and the impact of the disease on their sense of masculinity (Gray *et al.* 2002; Arrington 2003; Maliski *et al.* 2008) but less has been written about men's experiences of supportive care provision. The ideal study design for bringing these data together and creating an overview of men's experiences and needs is to conduct a qualitative systematic review and synthesis.

METHODS

Searches

The parent search strategy was devised and run in Medline and Medline in process (Appendix 1). Modified search strategies based on this search were run in Embase, Psych Info, CINAHL, British Nursing Index, IBSS and Sociological Abstracts. All searches were run from inception to July 2013.

Inclusion and exclusion criteria

Inclusion criteria for full-text articles were: qualitative studies that included men with a diagnosis of prostate cancer who were undergoing or had undergone any type of standard treatment (including active surveillance) that explored their needs for, attitude toward or experience of supportive care. These qualitative studies included ethnographic and observational studies, involving interviews and focus groups with men with prostate cancer. Two of the studies were longitudinal surveys that included qualitative data. Exclusion criteria were men at risk from prostate cancer, and men in end of life care.

Screening

References were screened by title and abstract by two reviewers and differences were resolved by discussion with a third person if necessary, and full articles were obtained that met the above criteria. The reference list of papers retrieved as full text were hand searched and key authors contacted.

Data extraction and synthesis

A thematic synthesis of the evidence in the qualitative papers was conducted, taking an interpretive approach. The reviewers adopted a 'thematic synthesis' approach (Thomas & Harden 2008). 'Descriptive themes' were drawn out of the data followed by the development of 'analytic themes' identified by the reviewers. The identification of themes was partly driven by the research question and partly grounded in the data. Data were extracted independently by at least two reviewers using customised forms and any discrepancies were resolved by discussion. All papers were reviewed by AJLK and additional reviewers including co-authors, members of the advisory group and patients with prostate cancer from a local support group. All included papers were critically appraised independently by two reviewers using the Critical Appraisal Skills Programme quality appraisal tool as an integral part

of the systematic review (CASP 2014). Disagreements around critical appraisal were resolved by discussion between the reviewers.

Findings were organised into 'first-order constructs' (the verbatim views and experiences of research participants) and 'second-order constructs' (the interpretations of the authors). Patient quotes ('first-order constructs') provide a significant voice of patient experience of supportive care in the analysis and discussion of the secondary qualitative data derived from the review papers. A framework was constructed in Excel with columns for first- and second-order constructs and a row for each article. Members of the research team met to identify and agree consensus on descriptive themes emerging across papers, incorporating all the first- and second-order constructs. The themes were summarised and mapped to show which articles had contributed to each theme. The development of descriptive themes remained very close to the constructs in the primary studies. Overarching analytic themes were subsequently identified, enabling synthesis of themes across studies and the development of new ideas.

RESULTS

The searches yielded 1684 articles excluding duplicates (Appendix 2). Twenty papers describing 20 individual qualitative studies were included in the synthesis, all published between 2004 and 2013 in Europe, the USA, Canada, Australia and the UK (Matsunaga & Gotay 2004; Boehmer & Babayan 2005; Broom 2005; Wallace & Storms 2007; Tarrant *et al.* 2008; Milne *et al.* 2008; Oliffe *et al.* 2009; Ream *et al.* 2009; Nanton *et al.* 2009; Ervik *et al.* 2010; O'Brien *et al.* 2010; Walsh & Hegarty 2010; Carter *et al.* 2011; Nanton & Dale 2011; O'Brien *et al.* 2011; Chambers *et al.* 2012; Galbraith *et al.* 2012; O'Shaughnessy *et al.* 2013; Rivers *et al.* 2012; Thomas 2013). Dual critical appraisal revealed that the papers were generally of good quality and none were excluded due to poor quality overall (see Appendix 3). Negative scoring on reflexivity and ethical considerations were not sufficient to warrant rejection of individual papers. If the papers had scored poorly on the other criteria, the reviewers would then have conducted a sensitivity analysis (Dixon-Woods *et al.* 2007). The study characteristics are included in Table 1.

Twelve descriptive themes emerged across the papers. They fall into three groups: (1) prostate cancer patients' experience of supportive care; (2) their accounts of unmet needs; and (3) their suggestions about how to improve supportive care. Table 2 lists the papers that contributed

to each of the 12 themes. The reviewers then developed three overarching themes that cut across the 12 descriptive themes. These were uncertainty, reframing and timing.

Prostate cancer patients' experience of supportive care

There were seven themes in this group: peer support, support from church communities, trusted other support, online support, communication with health professionals, the role of the prostate cancer specialist nurse and self-care. The analysis revealed that men's experience of supportive care was predominantly provided and influenced by informal networks of peer support or 'trusted others', and that formal support from health professionals was lacking.

Peer support

This was the most frequent theme to emerge, discussed in 10 of the 20 papers (Table 3). Peer support took different forms: support groups led by peers or by health professionals, and one-to-one peer support. Men were generally proactive in accessing this kind of support. Three papers described referral or signposting by health professionals (Table 3). Wallace and Storms (2007) describe that one study in which participant was told of support services by his urologist. The other papers referred mainly to one-to-one informal peer support found within patients' friendship networks, families, work colleagues, church group or leisure clubs.

I was fortunate in that I knew two or three men who had prostate cancer, so I found it very helpful to talk to them. (Wallace & Storms 2007: participant quotation)

Men's experience of peer support lifted them out of a sense of isolation and enabled them to talk about their illness experience, share information and exchange tips and ideas on dealing with treatment side effects. The reciprocal nature of talking and sharing was experienced as empowering. Galbraith *et al.* (2012) describes how it provided a sense of meaning in men's experience of the disease. However, he does not distinguish between informal one-to-one support or group support. Matsunaga and Gotay (2004) highlight the importance of reciprocity in such support. This had a positive effect on helping men to adjust to their diagnosis.

Many participants desired to help others who had been diagnosed and treated for prostate cancer as a way to provide meaningful outcome from their

Table 1. Study characteristics of review studies

Author and country of study	Stage of prostate cancer	Treatment stage and type of treatment	Aim of study	Theoretical approach	Method of data collection	Sample size	Age (years)	Ethnicity	Relationship
Boehmer and Babayan 2005 USA	Early stage prostate cancer	Pre-treatment phase	To determine men's sources of support during pre-treatment phase of prostate cancer.	Grounded theory	One-to-one interviews	21	37-70	6AA 1 L 14 W	16 m 5 unmarried
Carter <i>et al.</i> 2011 Canada	7-8 years since diagnosis. Advanced prostate cancer	After treatment, hormone refractory prostate cancer (17) - had chemotherapy - had hormone-sensitive prostate cancer (12) - had androgen deprivation therapy.	To understand unmet healthcare needs of men with advanced prostate cancer.	Qualitative description method	Interviews and focus groups	29	59-88	NA	23 m 5 w 1 div
Chambers <i>et al.</i> 2012 Australia	Advanced prostate cancer	After treatment, + during treatment - hormone therapy: 9. Hormone therapy: external beam radiation therapy; 11, brachytherapy; 3, radical prostatectomy; 3, orchiectomy; 1.	Examines a mindfulness-based intervention that was pilot tested for its accessibility and effectiveness for men with prostate cancer.	Interpretative phenomenological	Interviews	19	58-83	NA	16m/p 3w/div
Matsunaga and Gotay 2004 USA (Hawaii)	Does not state	Does not state	Examines what contributes to an enduring prostate cancer support group in a Hawaiian community.	Does not state	Interviews	24	55-85	17 A 7W	NA
Milne <i>et al.</i> 2008 Canada	Locally advanced prostate cancer	Short term after treatment (<6 months). Laparoscopic radical prostatectomy.	Men's experience following LRP. Pre-operative and post-operative needs.	Qualitative descriptive	Individual and focus group interviews	19	48-76	NA	19 m
Nanton <i>et al.</i> 2009 UK	4 weeks post-diagnosis to palliative care		To investigate the role of information in mediating the potential negative effects of uncertainty in prostate cancer, how men respond over time. Examined the perceptions and experiences of treatment and care of first-generation African-Caribbean men with prostate cancer.	Constant comparison method	Interviews and focus groups	22	55-85	NA	16m 2div 2w 2s
Nanton and Dale 2011 UK	Locally advanced prostate cancer.	After treatment. Prostatectomy (8) Radiotherapy hormones (2) Hormones (3) Surgery in last year (1) Catheter only (1) Watchful waiting (1)		Does not state.	Interviews	16	50-83	16 AC	11m 5w
O'Brien <i>et al.</i> 2011 UK	Locally advanced prostate cancer.	After treatment. Radical prostatectomy (12) Radiotherapy (9) Hormone (9) Watchful waiting (4) Monitoring following TURP (1)	To gain an insight into patients' experiences of follow-up care after treatment for prostate cancer and identify unmet psychosocial needs.	Constant comparison method	Interviews	35	59-82	NA	18 partners included in interview. Does not give RS for all 35 men. 12 m/p
Rivers <i>et al.</i> 2012 USA	Localised prostate cancer.	Not detailed	To explore the perceptions of African-American prostate cancer survivors and their spouses of psychosocial issues related to quality of life. Study explored the role and value of specialist nurses in prostate cancer care.	Ferrell's quality of life conceptual model.	Interviews	12	40-70	12 AA	NA
Tarrant <i>et al.</i> 2008 UK	Men who were recently tested or treated for prostate cancer.	On diagnosis. During treatment. After treatment. Newly diagnosed (3) Being actively monitored (without treatment) (7) Had curative treatment - prostatectomy, radiotherapy (17) Having hormone therapy.		Framework approach	Interviews	35	54-75	NA	NA

Table 1. Continued

Author and country of study	Stage of prostate cancer	Treatment stage and type of treatment	Aim of study	Theoretical approach	Method of data collection	Sample size	Age (years)	Ethnicity	Relationship
Walsh and Hegarty 2010 Ireland	Locally advanced prostate cancer	Long term after treatment. 15 years or less post radical prostatectomy	Aim was to provide a retrospective view of men's experiences of prostate cancer treatment from diagnosis to completion of surgery and beyond.	Does not state	Interviews	8	NA	NA	NA
Oliffe <i>et al.</i> 2009 Canada	Low grade prostate cancer on active surveillance for <2 years	Not detailed.	To examine what are men's psychosocial issues who are undergoing active surveillance with low grade PC.	Interpretative description	Interviews	25	48–77	19 W 7 O	19 m
Broom 2005 Australia	Locally advanced prostate cancer.	After treatment. Watchful waiting (2) Radical prostatectomy (15) External beam radiation (10) Brachytherapy (2) Hormone treatment (8) Cryosurgery (1) After treatment. Active surveillance (3) Endocrine therapy (7) Not detailed	Study explores men with prostate cancer experiences and perceptions of online support groups.	Charmz's approach to social analysis.	Interviews	33	40–85	33 W	NA
Ervik <i>et al.</i> 2010 Norway	Localised or locally advanced PC	Not detailed	Examines men's experiences living with localised or locally advanced PC.	Phenomenological hermeneutic approach	Interviews.	10	59–83	NA	9m 1s
Galbraith <i>et al.</i> 2012 USA	Not detailed.	Not detailed	To describe experiences reported by men over a 10 year period who have been treated for early stage PC.	Narrative content analysis	Open ended survey question content analysis.	401 longitudinal quality of life study	68 (mean.age)	337 W 64 O	364 partners enrolled in the study
O'Brien <i>et al.</i> 2010 UK	Men undergoing AM, those on hormonal treatment, those who have had curative treatment	Not detailed	To develop an understanding of experiences of follow-up patients with prostate cancer to examine unmet need.	Constant comparison method of data analysis	Interviews	35	59–82	NA	NA
O'Shaughnessy <i>et al.</i> 2013 Australia	All stages ex cluding palliative	Not detailed	To examine the supportive care needs of men diagnosed and treated for prostate cancer and their partners.	Thematic approach	Interviews and focus groups	193	60–75	NA	148 w/p
Ream <i>et al.</i> 2009 UK	All stages	Not detailed	To investigate prostate cancer nurse specialist roles.	Framework analysis.	Interviews	40	47–86	39 W 1 AC 10 W	30 m/p 10 w/s 2 p 8 s
Thomas 2013 Australia	Long term after treatment (>6months). Average time from diagnosis to participation in focus group was 26 months.	Prostatectomy (7) Radiation therapy (2) Active surveillance (1)	To examine experiences of gay and bisexual men following a prostate cancer diagnosis.	Stigma theory.	On-line focus group	10	47–70	10 W	
Wallace and Storms 2007 USA	Diagnosed between 6 months – 12 years.	Not detailed	To explore the psycho-social needs of men with prostate cancer and effectiveness of support services.	Grounded theory	Focus groups	16	49–81	15 W 1 AA	15 m 1 div

AC: African-Caribbean; AA: African-American; A: Asian; W: White; L: Latino; O: Other.

Table 2. Reviewers' themes

Reviewers' theme	Description of reviewers' themes	Papers where reviewers' theme appears. Numbers refer to articles as they are listed in Table 3
ED/UI Erectile Dysfunction/ Urinary Incontinence	Impact of treatment side effects; priority of side effects; emotional needs; functional needs. Timing about being asked about ED/UI by HPs. ED/UI – impact on longer term psycho-social needs, seen as unmet needs by patients. UI/ED as restrictions on everyday life: 'can't go back' to 'normal' life. Patients not being informed about the possible severity and length of ED/UI symptoms pre-treatment.	6, 10, 11, 12, 13, 14, 15, 17, 18, 20
Peer support	Value attached to peer support in a support group setting, group identification, and sense of belonging. Value attached to one-to-one peer support, patients suggested that this was their most favoured form of support, reflected by their experience. Reciprocal nature of peer support – impact of giving and receiving support. Being involved with peer support can help normalise men's experience with prostate cancer. Fact that peer support can be an informal source of support (one-to-one peer support) found within the community.	1, 3, 4, 6, 8, 9, 10, 11, 12, 13, 14, 16, 17 Experience of one-to-one peer support in: 1, 4, 6, 9, 10, 12, 13, 14, 16, 17
Emotional support and emotional needs	Patients' feeling that there is a lack of understanding by others of the emotional impact of prostate cancer, people who have not experienced the disease. Value put on emotional support – longer term emotional needs. Extent of emotional impact of diagnosis and treatment, and emotional needs.	1, 2, 7, 11, 13, 17, 18, 20
Trusted other/ partner support	Significant value attached by men to support provided by trusted other/partners. Trusted others cited as main source of support. On the other hand others found it difficult to talk to spouses/partners about their prostate cancer (10,18,19). Men without trusted other support benefited from health professional support.	1, 2, 6, 10, 14, 15, 18, 19, 20
Communication with health professionals	Communication with health professionals around diagnosis, and around changes in sexual function post-treatment. Difficulty with communication with HPs. Lack of empathy of HPs. Includes patients asking for help from HP or not asking for help. Not being asked about psychological needs, or about sexual function.	6, 8, 15, 10, 11, 12, 13, 17, 20
Online support	Men who seek online support for prostate cancer. Benefits of online support – sharing vulnerability and disease experience with other men, + anonymity. Different uses of online support groups. Those men who don't use online support.	3
Spiritual support	Spirituality as a coping mechanism. Belief that decisions of life belong to God. Both papers discuss experience of either African-American or African-Caribbean men.	14, 19
Communication	Communication with spouse/partner about diagnosis, change in sexual function. Communication with 'trusted others', family and friends about diagnosis.	8, 11, 19, 20
Information	Patient dissatisfaction with medical information they have received, particularly treatment side effects, or information about supportive care. Timing of information, not receiving adequate information at the right time (e.g. on treatment/treatment side effects). Information enables patients to be in control.	2, 4, 6, 9, 10, 12, 13, 14, 19
Specialist nurse	Accessibility to a cancer specialist nurse. Qualities shown by CSN. Importance of CSN role as a patient advocate. CSN as source of supportive care. Timing of appointment with CSN was key. Importance of CSN giving patients prostate cancer diagnosis.	5, 8
Self-care	Self-care relates to patients' self-management of their disease, including making lifestyle changes such as diet and exercise. Self-care as taking control of illness.	4, 6, 7, 9, 14, 17, 18, 19, 20
Suggestions	Need for supportive care. Impact of experience of supportive care. Suggestions related to unmet needs – psychological and emotional needs. Other patients suggested strategies to improve care delivery.	4, 5, 10, 13, 17, 18

Authors: (1) Matsunaga and Gotay 2004; (2) Boehmer and Babayan 2005; (3) Broom 2005; (4) Wallace and Storms 2007; (5) Tarrant *et al.* 2008; (6) Milne *et al.* 2008; (7) Oliffe *et al.* 2009; (8) Ream *et al.* 2009; (9) Nanton *et al.* 2009; (10) Ervik *et al.* 2010; (11) O'Brien *et al.* 2010; (12) Walsh and Hegarty 2010; (13) Carter *et al.* 2011; (14) Nanton and Dale 2011; (15) O'Brien *et al.* 2011; (16) Chambers *et al.* 2012; (17) Galbraith *et al.* 2012; (18) O'Shaughnessy *et al.* 2013; (19) Rivers *et al.* 2012; (20) Thomas 2013.

Table 3. Types of peer support

Paper	One-to-one peer support	Support group	Peer led support group	Health professional led support group	Patient referred by health professional to support
Matsunaga and Gotay 2004			X		X
Wallace and Storms 2007	X				
Milne <i>et al.</i> 2008	X				
Nanton <i>et al.</i> 2009	X				
Ervik <i>et al.</i> 2010	X				
Walsh and Hegarty 2010	X	X	Does not detail	Does not detail	
Carter <i>et al.</i> 2011		X		X	
Nanton and Dale 2011	X				
Chambers <i>et al.</i> 2012		X		X (Mindfulness CBT group facilitated by psychologists)	X
Galbraith <i>et al.</i> 2012	X				

challenges with prostate cancer and its treatment. (Galbraith et al. 2012: author quotation)

Once you go through the procedure, you feel like you could be of assistance, especially about the operation and what to expect. (Matsunaga & Gotay 2004: participant quotation)

The value of peer support was evident at all stages of prostate cancer with diagnosis, treatment decision making and advanced disease being three critical times.

[diagnosis was] such an emotional thing that I needed to be with people who had gone through this or were going through it. (Wallace & Storms 2007: participant quotation)

Participants felt that the ideal support programme should be made available immediately after diagnosis so that they could literally 'walk out of the urologist's office and begin to discuss options'. The participants were most interested in meeting with other men with the disease, not a physician or a nurse. (Wallace & Storms 2007: author quotation)

I finally found a fellow around the corner from me and he came over to my house. We had coffee; we got to be pretty good friends and he kind of sold me on the laparoscopic. (Milne et al. 2008: participant quotation)

Being in a mixed group with men at different stages of prostate cancer helped men confront and accept disease progression:

For me, who was newly diagnosed in the middle of treatment, to people who had been diagnosed for 15 or 16 years . . . it may have been confronting but I didn't find it so because they seemed to be able to cope with it and that was reassuring. (Chambers et al. 2012: participant quotation)

Carter's study focuses on men with advanced disease in which men were looking for information rather than emotional support. However, not all men found it useful, and some men stopped going when they felt they were no longer learning new information (Carter *et al.* 2011).

Support accessed within a church community

Two papers referred specifically to peer support accessed through their local church. One paper reports the experience of African-Caribbean men in the UK (Nanton & Dale 2011) and another focuses on African-American men in the USA (Rivers *et al.* 2012). They recount how participants attended church services more frequently and became more involved in church activities after diagnosis. Their church community facilitated access to other men with prostate cancer from whom patients could get information on diagnosis and treatment. This networking helped some men to 'find their voice' and become advocates for others:

. . . there's been several men within my church and in my community that has . . . (prostate cancer) . . . when I found out that he was goin' through it, I went up . . . we sat down and talked about it and so it's . . . it's made me somewhat of an advocate. (Rivers et al. 2012: participant quotation)

Support from a partner or 'trusted other'

Wives, partners, friends and families were described as significant sources of support by men in six papers (Matsunaga & Gotay 2004; Boehmer & Babayan 2005; Ervik *et al.* 2010; Walsh & Hegarty 2010; O'Shaughnessy *et al.* 2013; Rivers *et al.* 2012). Boehmer and Babayan (2005) coined the phrase 'trusted other' in recognition that other key individuals, apart from a spouse, may fulfill this role. Ambivalence was expressed about how much to dis-

close to close family. Men recognised that family members have their own emotional reactions to cope with. For some men the need to retain their 'normal' lifestyle despite their diagnosis was paramount.

... and our son, he doesn't say much, he doesn't show a lot of feelings, but our daughter had a hard time ... I don't know maybe men are more tough in such cases ... now I have a more open attitude towards illness and that sort of question. Earlier in life, I had a much more tough attitude. ... (Ervik et al. 2010: participant quotation)

I mean I only told my wife and nobody else from the day I was informed ... So my lifestyle didn't change one iota ... because we didn't want to upset them. We could handle it. (Walsh & Hegarty 2010: participant quotation)

Ervik et al. (2010) stresses the importance of support from spouses but several papers highlight the need for spouses to also receive support. For example, concern was raised about spouses' ongoing ability to adequately care for and support them during and after treatment (Boehmer & Babayan 2005; Rivers et al. 2012):

Some of the women expressed feeling overwhelmed by the caretaker role. ... Some feared how this were to change their relationship, were they cast in the nurse role. (Boehmer & Babayan 2005: author quotation)

Online support

The internet was cited as a source of information by men in five studies (Boehmer & Babayan 2005; Wallace & Storms 2007; Milne et al. 2008; Carter et al. 2011; Rivers et al. 2012). Milne highlights the need for nurses to guide patients to reliable information sources. One article focuses on the experience of men using online support groups in Australia (Broom 2005). Men described how engaging with others online as opposed to face-to-face reduced their inhibition; they valued the anonymity in accessing and receiving support and information.

Some men don't want to be face to face. Maybe they're frightened of it ... maybe they're scared of being ridiculed ... maybe they're a bit anxious about having the problem and not wanting to share it. I think that's men for you. (Broom 2005: participant quotation)

Some men took a passive role, observing how others responded to prostate cancer and how they were coping without divulging their own experience. Some men found

that the online medium enabled them to distance themselves from their disease.

Communication with health professionals

Several papers describe patients' difficulties in talking to health professionals about important issues early on post diagnosis, when many appeared not to have a clear understanding of PSA testing or what a biopsy is.

I think GPs should make a point of saying what it is about and why it's being done at a particular time. (Walsh & Hegarty 2010: participant quotation)

Walsh and Hegarty (2010) highlight that several men in her study did not feel that their general practitioner (GP) had communicated adequately on what the PSA test was and its significance.

So he came up to me and said he was going to do blood tests the next day. Now no one ever told me not even my GP that the blood test was called a PSA. (Walsh & Hegarty 2010: participant quotation)

When looking back at their diagnostic appointment (given in some cases by a hospital consultant, a GP or sometimes by specialist nurses) patients singled out that this was not handled with sufficient sensitivity (Wallace & Storms 2007; Nanton & Dale 2011). Communication difficulties also continued long term after treatments (Ervik et al. 2010; Thomas 2013).

Men also reported poor communication with health professionals about the potential severity and duration of side effects of treatment, so patients felt unclear about what to expect (Ream et al. 2009; Thomas 2013), USA (Galbraith et al. 2012), Norway (Ervik et al. 2010) and Australia (Broom 2005).

Three reasons for this difficulty in communication emerged across papers. First, patients felt unable to talk about changes in sexual function, because for the most part, they were not asked about this at an appropriate time or in a suitable context.

Men can be reluctant to volunteer information on erectile function but generally respond with relief when the question is asked. (Milne et al. 2008: author quotation)

Second, men said that they could not easily discuss psychological issues with health professionals owing partly to their experience of a lack of continuity of care.

I think if you saw the same person each time you would probably build up a rapport with that person. But seeing a stranger every time you're thinking 'oh

my God I'm not going to walk in there and start talking about my sex life with someone I've never seen in my life before . . . I think I glossed over it [the psychological impact]. (O'Brien et al. 2011: participant quotation)

It was quite a shock when you go there and it's somebody else . . . I don't think I spoke about my psychological problems. (O'Brien et al. 2011: participant quotation)

Third, men felt that there was a lack of empathy shown by health professionals, leaving them feeling depersonalised.

Cavalier attitudes expressed by the treatment team were disquieting . . . We were treated liked test subjects, not equals. (Galbraith et al. 2012: participant quotation)

This prevalent finding may be summed up by Ervik et al. (2010) who describe what he calls the 'silence of the healthcare system'. This patient is referring to his follow-up appointment with a physician:

It is never really time for it . . . he was not that good with words. (Ervik et al. 2010: participant quotation)

Thomas's (2013) article suggests that participants perceived GPs to be more empathetic than urologists:

In marked contrast to the perception of the urologists, most participants were satisfied with the role of their general practitioner in the prostate cancer journey. The local GPs . . . were thought to be empathetic to the experiences of the participants. (Thomas 2013: author quotation)

Experience of a cancer specialist nurse

Men who had received care from a cancer specialist nurse reported a positive experience of enabling them to discuss non-medical aspects of their illness (Tarrant et al. 2008; Ream et al. 2009). This was exemplified by the way nurses communicated the diagnosis (Ream et al. 2009) and could act as patient advocates by accessing appropriate care and support. Another key element of the specialist nurse role was in terms of long-term and ongoing care (O'Shaughnessy et al. 2013), and the fact that contact could be initiated by the patient.

. . . men with prostate cancer would utilize the services of a specialist prostate cancer nurse at all stages of the prostate cancer journey. (O'Shaughnessy et al. 2013: author quotation)

Key stages when men valued specialist nurse input was around treatment decision making and treatment choice after initial hormone therapy has failed (O'Shaughnessy et al. 2013). Specialist nurses sometimes arranged or referred patients to support groups (Tarrant et al. 2008) and played a role in helping men reframe their illness experience in a positive way, enabling better adaptation and coping skills.

She's the link, the liaison and to me the liaison officer, or whatever you want to call it . . . the surgeon, the consultant is very important but only at a specific time. The one you are relying on most is the (prostate cancer specialist nurse). (Ream et al. 2009: participant quotation)

It worried me to death..I felt I had to ring (the specialist nurse) . . . I was asking myself questions I couldn't answer . . . after I spoke to her I felt a lot better. Oh, I can ring (the specialist nurse) up any time I want to. (Tarrant et al. 2008: participant quotation)

Tarrant states that patients who saw a specialist nurse were more likely to have received written information and clear explanations about their tests, treatment options and sources of support (Tarrant et al. 2008).

Self-care

Self-care is discussed in nine of the papers. Several authors discuss the empowerment and sense of control that comes from self-care and making lifestyle changes such as diet and exercise.

[By] taking an active part in their own health management [through making changes in their diet and/or exercise] men were taking control of their illness. (Nanton et al. 2009: author quotation)

This was particularly true for men with advanced hormone-resistant cancer who were most likely to have changed their diet and lifestyle (O'Shaughnessy et al. 2013).

For the last four years, . . . eating better, exercising more . . . and living life more fully. (O'Shaughnessy et al. 2013: participant quotation)

Other aspects of self-care include taking an 'active problem solving approach' to illness by, for example, joining a support group (Nanton et al. 2009), returning to work or seeking out social and emotional support from family, friendship and faith networks (Rivers et al. 2012; Nanton & Dale 2011).

Self-care is particularly important for prostate cancer patients who are under active surveillance. They tried to combine 'living a normal life' with 'doing something extra', using strategies similar to men at other stages of disease and treatment such as making dietary or lifestyle changes, and engaging with their partner, family and friends (Oliffe *et al.* 2009; O'Shaughnessy *et al.* 2013). The authors emphasise the significance of men's wives and partners in helping men to make lifestyle changes.

Patients' accounts of unmet supportive care needs

There were three themes in this group: need for emotional support, need for support to deal with treatment side effects, in particular changes in sexual function and urinary incontinence, and need for information. A major concern is the difficulty that men experienced in actually broaching sensitive subjects with health professionals (Milne *et al.* 2008; Ream *et al.* 2009; Ervik *et al.* 2010; Galbraith *et al.* 2012; Thomas 2013).

Need for emotional support

Men described their long-term need for emotional or psychological support, beginning at diagnosis and continuing through treatment into survivorship (Oliffe *et al.* 2009; Ream *et al.* 2009; Ervik *et al.* 2010; O'Brien *et al.* 2010; Galbraith *et al.* 2012; O'Shaughnessy *et al.* 2013; Thomas 2013). They felt that there was a lack of understanding by health professionals in primary and secondary care of the emotional impact of prostate cancer particularly in the longer term (Matsunaga & Gotay 2004; Boehmer & Babayan 2005; Oliffe *et al.* 2009; O'Brien *et al.* 2010; Thomas 2013). O'Shaughnessy *et al.* (2013) define 'psychosocial' needs as men's fears around treatment, anxiety and depression, changes in sexuality, masculinity and relationships. O'Shaughnessy *et al.* (2013) and Boehmer and Babayan (2005) highlight that men's distress and need for psychological support is especially evident when they are first diagnosed and Boehmer and Babayan refer to a later peak of distress if their cancer reoccurs.

The estrangement of men from 'softer' psychosocial healthcare services was especially evident in how few ideas or recommendations were offered by the study participants when directly asked about what services and how services might best support them. (Oliffe et al. 2009: author quotation)

Carter *et al.* (2011) highlight the need for psychological support to be ongoing. O'Brien *et al.* (2010) and Galbraith *et al.* (2012) talk about the need for support through the psycho-emotional responses to survivorship.

Participants strongly expressed the need for the health care team to acknowledge their experiences of uncertainty, anger, and grief or loss. (Galbraith et al. 2012: author quotation)

Need for support to deal with treatment side effects – changes in sexual function and urinary incontinence

Several of the papers highlighted the need for emotional and psychological support for treatment side effects, primarily urinary incontinence and erectile dysfunction.

The follow-ups (at the hospital) . . . have been more concerned with the physical side of things, not the mental side of it . . . there could have been more emphasis on (that). (O'Brien et al. 2011: participant quotation)

O'Brien *et al.* (2011) highlight that assessment of psychosexual needs has to take place throughout the follow-up period, not only at the time of initial treatment, particularly because 'patients may take time to identify that they have a need for psychosexual support'. O'Brien points out that there may be a role for GPs in assessing wider psychosexual needs and signposting where to get help, and to include patients' partners in this. Galbraith suggests that specialist nurses are in a key position to offer support for men's relational and emotional needs.

Men in several studies expressed a need for information on the severity and duration of incontinence and erectile dysfunction side effects, as well as practical support (Milne *et al.* 2008; Walsh & Hegarty 2010; Carter *et al.* 2011; Nanton & Dale 2011; O'Brien *et al.* 2011; Thomas 2013). Men said they lacked help and support in dealing with these. Difficult reactions to surgery were common:

If I had known what was gonna happen, they'd never have done it . . . They must have cut muscles and everything. And I'll tell you, your sex life is gone. . . . I should have been filled in. (Carter et al. 2011: participant quotation)

Immediately postoperatively the question of impotence doesn't really come into your head . . . I think it's only later on that you have to . . . face up psychologically to how you handle that . . . There's not a lot of counselling form either the primary care or the hospital in terms of the psychological aspect. (O'Brien et al. 2010: participant quotation)

Need for information

Information can help empower patients to feel more in control of their disease through increased understanding.

Acquiring knowledge allows patients to be in control because it increases their level of understanding'. He highlights the importance of acquiring first-hand knowledge from other men with prostate cancer. (Milne et al. 2008)

Across the articles, men reported receiving information about prostate cancer and its treatment from a variety of sources including oncologists, urologists, nurses, GPs, cancer charities, the internet, friends and family members. A major and valued source of information is through peer networks (Matsunaga & Gotay 2004; Wallace & Storms 2007; Milne et al. 2008; Walsh & Hegarty 2010).

In relation to information from health professionals, there were two issues: content and timing. In Matsunaga and Gotay's (2004) study, men said that physicians did not give them enough information about treatment options and assumed they understood more than they really did. In three studies (Wallace & Storms 2007; Tarrant et al. 2008; Nanton et al. 2009), men expressed a need for information after diagnosis on what the PSA test was and what changes in it meant, and on appropriateness of treatment and treatment options. Timing was sometimes felt to be inappropriate, e.g. when they received information on treatment side effects, it was often too little too late. As a result, men felt unprepared for the severity and duration of these side effects (Milne et al. 2008; Carter et al. 2011; Nanton & Dale 2011). One study participant highlighted that it is hard to absorb information directly upon diagnosis:

No you can't absorb it and that's in a way one little criticism of (the specialist) nurse . . . 'you've got prostate cancer' . . . and she carts you off into a tiny little cubicle of a room..and I don't know what the hell she said because . . . that was too soon. . . . I was in a state of numbness..at that point and so I don't really know what she was trying to achieve. (Tarrant et al. 2008: participant quote).

The importance of including both men and their partners in information provision on treatment and side effects was highlighted by Rivers et al. (2012) and O'Shaughnessy et al. (2013). The 'need for information' theme highlights the lack of communication between patients and health professionals particularly in relation to who communicates it, and at what point in the care pathway.

Men's suggestions for improved delivery of supportive care

There were two themes in this group: need for information and need for more time with a specialist cancer nurse

(to provide practical, emotional and psychological support). Suggestions were forthcoming from the men themselves, across many articles, as to priority areas for targeting improvements. In terms of information, they suggested making more disease-related information available at or shortly after diagnosis (Tarrant et al. 2008). They also suggested that assistance be provided in interpreting the information (Matsunaga & Gotay 2004).

Another suggestion was to make more contact time available with a cancer specialist nurse, particularly after diagnosis and after active treatment (Tarrant et al. 2008). Emotional and psychological support for both patients and their partners was flagged up as an important area for improvement (Wallace & Storms 2007; Carter et al. 2011). Ervik et al. (2010) stated that when asked directly, half of the men in his study would consider organised counselling if this were an option.

Overarching themes

The reviewers developed overarching analytic themes that cut across the 12 descriptive themes within the papers: uncertainty, reframing and timing of support.

Uncertainty

Men's experience of the prostate cancer pathway was full of uncertainty and anxiety (Milne et al. 2008; Oliffe et al. 2009; Nanton et al. 2009; Ervik et al. 2010; O'Brien et al. 2010; Walsh & Hegarty 2010; Carter et al. 2011; Nanton & Dale 2011; Galbraith et al. 2012; O'Shaughnessy et al. 2013; Rivers et al. 2012; Thomas 2013). Uncertainty was associated with a perceived lack of information provision linked to treatment options and outcomes, about the extent and severity of treatment side effects, and likely prognosis. Uncertainty was particularly pronounced in men under active surveillance (Oliffe et al. 2009) particularly around the time leading up to PSA testing, and for those with advanced or recurrent disease (Nanton et al. 2009). Even the care pathway seemed to be uncertain for some men who did not fully understand the link between their illness experience and the process of care, for example, not knowing when events in their care were going to take place and who was responsible for particular aspects of their care (Nanton et al. 2009).

Reframing

The theme of 'reframing' arises as a means of coping with uncertainty. The term 'reframing' was used in two of the articles (Nanton et al. 2009; Thomas 2013), but the

concept was relevant across many more. Galbraith's description of men adapting to a 'new normal' is conceptually similar. Reframing can be a positive way whereby patients dealing with uncertainty about a prostate cancer prognosis determine a positive reconstruction of the situation, thus giving mental shape to an uncertain future. Reframing can also help allay unrealistic hopes to return to a pre-treatment level of functioning (Galbraith *et al.* 2012).

Over half the participants found a new appreciation for living in the 'Now' and expressed an appreciation of the love and support of those close to them. There was a re-evaluation as to what was really important in the lives of a number of these men. (Thomas 2013: author quotation)

A participant in this study felt that his diagnosis had given him the opportunity to reframe his sense of his sexuality and of being a gay man.

The process of reappraisal and reframing was evident across all patient groups including older men and those with advanced disease, although it was harder for patients with metastatic disease (Nanton *et al.* 2009). Reframing can be facilitated by support from an individual or a group. For example, the specialist nurse can play a role in the process:

*[the nurse] was instrumental in making me feel positive about everything rather than feeling negative . . . instead of 'dying of cancer' you are 'living with it. (Ream *et al.* 2009: participant quotation)*

Reframing also took place during patients' experience of a peer support group by using the information they had gained through their illness experience to help others in the group.

. . . through participation in support group activities for example, anxiety over their own situation was displaced . . . by the process of doing something useful. . . . men demonstrated the possibility of a positive response in the face of an uncertain future. (Matsunaga & Gotay 2004: author quotation)

Timing of support

A trajectory becomes evident in the included studies, from early information needs to later psychological needs, and ongoing support for psychosexual needs. Many articles portray men as relatively uninformed about prostate cancer before and after their diagnosis, and even post-treatment in some cases (Wallace & Storms 2007; Walsh & Hegarty 2010; Nanton & Dale 2011). A key time for

information provision is between testing and diagnosis and before a consultant appointment. Men reported failing to gain a good understanding of treatment and side effects, their severity and longevity. Information at this stage would help patients to realistically appraise or 'reframe' their experience and put plans in place to effectively deal with the consequences of treatment. Diagnosis is inevitably a difficult time and for some men their psychological support needs begin here. It can be difficult to retain information given out at this stage (Thomas 2013).

DISCUSSION

The provision of supportive care must be carefully targeted in terms of its content and the timing of delivery. Men experienced uncertainty, lack of information and poor communication with their medical team about the nature of diagnostic tests, the extent of treatment side effects and the likely progression of the disease. Communication with their medical team about these issues was limited and difficult. This was ameliorated if a specialist nurse was in the team. Some of the uncertainty experienced by men reflected inherent problems in treating prostate cancer, such as the uncertainty around disease progression and clinical equipoise around treatments.

There appears to be a strong link between patients' need for information and individual levels of uncertainty. Information to ameliorate uncertainty and its consequent anxiety was not forthcoming, and men reported a lack of information about any support that might be available. Men received most of their information and support from peer groups or individuals but not all managed to access these resources.

Uncertainty as a theme has emerged in previous studies of prostate cancer patients where it has been shown to 'adversely influence patients' and their spouses' quality of life (Bailey *et al.* 2007; Shaha *et al.* 2008). Some men deal with uncertainty by focusing their attention on their work life or engaging in self-care strategies, such as using complementary medicines (Bailey *et al.* 2007). Uncertainty also emerges as a theme in the literature of health and illness more widely. Mishel (1990) defines uncertainty as 'the inability to determine the meaning of illness-related events. It is a cognitive state created when the individual cannot adequately structure or categorize an illness because of insufficient cues'. Mishel proposes that managing uncertainty is critical to adapting to illness and that people cognitively process events linked to illness and construct meaning from them. Uncertainty is reappraised over time; it may not be resolved but may become part of people's reality (Mishel 1990; Bailey *et al.* 2007). Open

discussion between patients and health professionals in a one-to-one or group setting may facilitate this process. This theme highlights the need for individual assessment of levels of uncertainty and coping in patients, in order for health professionals to identify areas of need, support and information for patients and families.

Reframing is one possible way of supporting men with prostate cancer around uncertainty. There is a link between reframing and self-care in that some men in the studies (Milne *et al.* 2008; O'Shaughnessy *et al.* 2013) who felt an overwhelming need to regain control of their lives by returning to pre-operative activities, and a need to develop a renewed sense of self. The wider literature on prostate cancer also discusses peoples' experience of reframing their illness experience (Lepore & Helgeson 1998; Bailey *et al.* 2007). In discussing the reframing process, Bailey *et al.* (2007) refers to cognitive reframing, which helps men as '*they attempt to incorporate the experience of prostate cancer and watchful waiting in to their life structure*'. Bailey highlights the importance of positive appraisal of the disease in order to enhance quality of life and stresses the ways in which nurses can help men with prostate cancer with this process. This review reveals that men can experience reframing of their illness experience directly for themselves or be encouraged to do this by health professionals in a more formal context (referred to in the wider literature as cognitive reframing (Bailey *et al.* 2007).

Information on the process of care, the timing of events and treatment and responsibility for care has also been highlighted as an unmet need (Nanton *et al.* 2009). To facilitate the delivery and retention of information, the presence of a partner or 'trusted other' at the appointment could be encouraged; information could be given in written form and reinforced at subsequent appointments along the disease pathway, for example by a specialist nurse (Tarrant *et al.* 2008). While some men need specialised support such as psycho-sexual counseling, for many men peer support meets their needs.

Strengths and limitations to the study

The strengths of this study are that it is to our knowledge the first qualitative review and synthesis to be conducted on the experience of, and need for supportive care for men with prostate cancer in the literature and uses rigorous systematic review and qualitative synthesis methodology. Thematic synthesis was chosen as it addresses questions of intervention need, appropriateness and acceptability.

A limitation of this review was that articles focusing specifically on diagnosis and treatment decision making

were excluded from this review. The included review papers were predominantly from North America so the authors' findings may not be universally applicable. The overall quality of the papers was good and contributed significantly to the discussion on prostate cancer and supportive care. The review identifies that there are few papers on the experience of men from minority ethnic groups, single men and gay men, highlighting a need for future research with these populations.

CONCLUSIONS

The review concludes that the most valued form of support men with prostate cancer experience is one-to-one peer support and support from partners. The review also shows that men perceive support groups to have two different roles, that of information giving (particularly when health professional led) and emotional sharing (peer led). Some men indicated the need following diagnosis to be referred by health professionals to one-to-one peer support, or to local support groups. This review also highlights the need for improved access to cancer specialist nurses throughout the care pathway, individually tailored supportive care and psychosexual support for treatment side effects.

IMPLICATIONS FOR PRACTICE

There is a need for more timely and accurate information and resources to help manage daily living impacted by treatment side effects. For some men, this may translate into a need for access to psychosexual and specialist support.

Positive experiences with health professionals were considered to improve health outcomes. The practice implications of this study's findings are the need to improve access to cancer specialist nurses at key points in men's disease progression and care pathway.

Men in the included studies indicated a need for individually tailored care packages based on needs and changing needs.

There is also a need for healthcare professionals to acknowledge patients' uncertainty, and emotional responses in dealing with prostate cancer.

Health professionals also need to encourage self-care of patients with prostate cancer and their partners, and to provide information and support to encourage this.

In view of the significant role played by partners, there is a need for health professionals to acknowledge the 'care burden' on partners/significant others and provide access to support.

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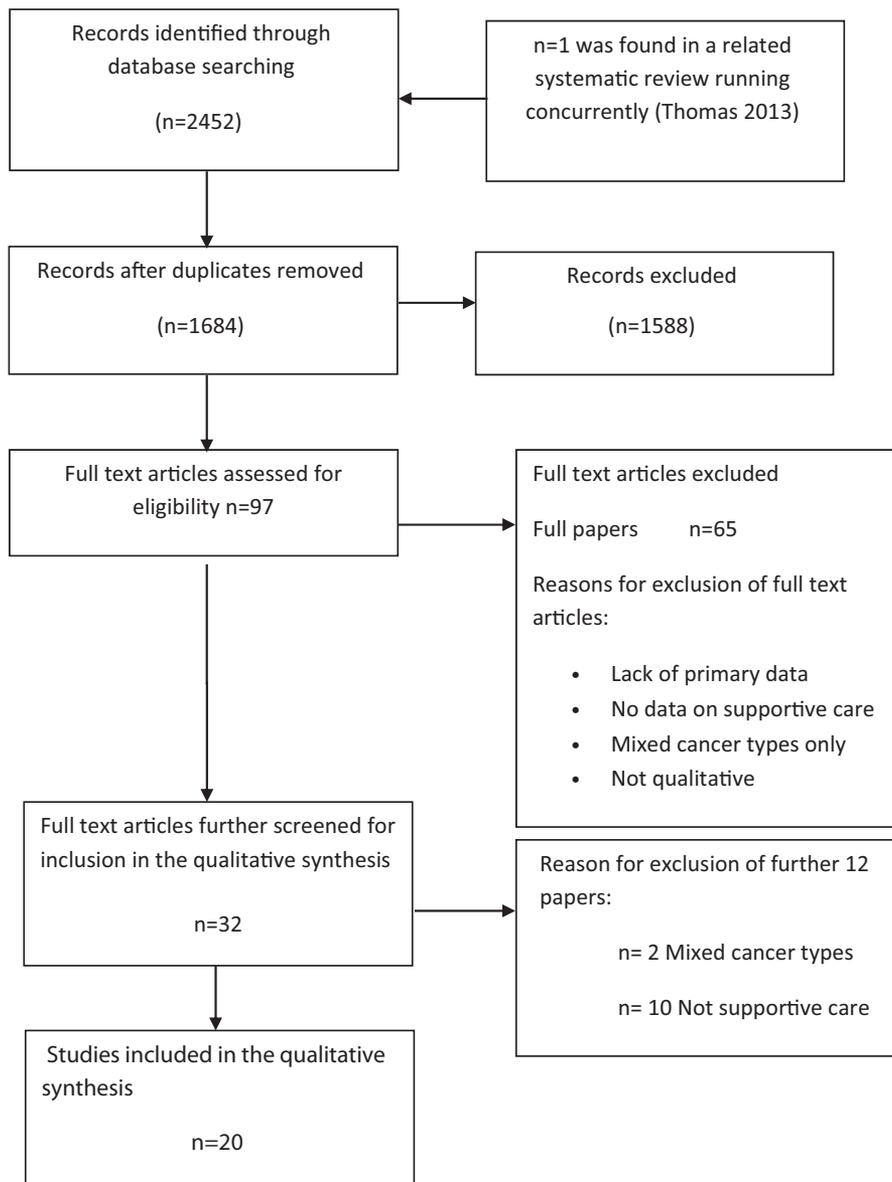
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APPENDICES

Appendix 1 Medline Search Strategy run July 2013

1. Medline: exp prostatic neoplasms/
 (prostat\$ adj4 cancer\$).tw.
 (prostat\$ adj4 neoplas\$).tw.
 (prostat\$ adj4 carcinoma\$).tw.
 (prostat\$ adj4 tumo?:r\$).tw. OR
 Qualitative research
 Semi-structured questionnaire
 Interviews
 Observation methods
 Patient narrative
 Patient experience
 Nvivo

APPENDIX 2 PRISMA FLOW CHART OF REVIEW



APPENDIX 3 CRITICAL APPRAISAL SKILLS PROGRAMME (CASP) EVALUATION OF INCLUDED STUDIES

Article	Was there a clear statement of the research aims?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Were the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Broom, 2005 Journal of Sociology Australia	Y	Y	Y	Y	Y	N	N	Y	Y	Does contribute to ideas on internet use as source of support.
Boehmer and Babayan, 2005	Y	Y	Y	Y	Y	N	Y	Y	Y	Quite but doesn't discuss findings in relation to current practice or policy.
Carter <i>et al.</i> 2011 Canada	Y	Y	Y	Y	Y	N	Y	Y	Y	Very valuable in relation to its implications for nursing interventions
Chambers <i>et al.</i> 2012 Australia	Y	Y	Y	Y	Y	N	Y	Y	Y	Valuable for services working with men with advanced PC.
Ervik <i>et al.</i> 2010 Norway	Y	Y	Y	Y	Y	N	Y	Y	Y	
Galbraith <i>et al.</i> 2012 Matsumaga & Gotay 2004 USA	N	Y	Y	Y	Y	N	N	Y	Y	Discusses implications for practice. Good discussion. Contributes to the literature.
Milne <i>et al.</i> 2008 Canada	Y	Y	Y	Y	Y	N	Y	Y	Y	Well structured paper. Good on detail.
Nanton <i>et al.</i> 2009 UK	Y	Y	Y	Y	Y	N	Y	Y	Y	Discussion links findings with wider policy context.
Nanton and Dale, 2011 UK	Y	Y	Y	Y	Y	Y	Y	Y	Y	Contributes to research AC men with PC, of which very little exists. Good discussion + discusses implications for policy and practice.
O'Brien <i>et al.</i> 2010 UK O'Brien <i>et al.</i> 2011 UK	Y	Y	Y	Y	Y	N	Y	Y	Y	
O'Shaughnessy <i>et al.</i> 2013 Australia	Y	Y	Y	N	Y	N	Y	Y	Y	Yes because it contributes to the small amount of available literature on supportive care + PC. Discusses practice implications.
Oliffe <i>et al.</i> 2009 UK	Y	Y	Y	Y	Y	N	Y	Y	Y	Does discuss implications for practice.
Ream <i>et al.</i> 2009 UK	Y	Y	Y	Y	Y	N	Y	Y	Y	Highlights lack of research in this area.
Rivers <i>et al.</i> 2012	Y	Y	Y	Y	Y	Y	Y	Y	Y	Valuable because examines men's needs and perspectives of specialist nurses. Valuable as contributes to support needs of African-American couples. Few papers on this.
Tarrant <i>et al.</i> 2008 UK	Y	Y	Y	Y	Y	N	N	Y	Y	Identifies the need for further research. Discusses policy and practice implications.
Thomas, 2013 Australia	Y	Y	Y	Y	Y	N	N	Y	Y	There are few papers on this topic therefore this paper contributes to the field. It also identifies the need for further research.
Wallace and Storms, 2007 USA	Y	Y	N	N	Y could have also done individual interviews	N	N	N	Y	Identifies the need for further research on unmet need.
Walsh and Hegarty, 2010	Y	Y	Y	Y	Y	Y	Y	N	Y	Good discussion on needs and support.